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Evaluating the Use of a PRO Questionnaire in Clinical Practice

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Abstract. Aalborg University Hospital in Farsø uses data from a patient-reported outcome (PRO) questionnaire in order to predict if patients diagnosed with osteoarthritis will benefit from surgery. The purpose of including PRO in the decision-making is to ensure quality and transparency, to include patients in their own treatment, and to make the patients central to both the decision-making and the dialogue. Our evaluation of the use of the PRO questionnaire is based on the observation of patients filling out the questionnaire and interviews with 7 patients and a doctor. We found that there were several usability issues especially for the patients, such as navigation problems and a lack of consistency in the layout of the measurement scales. Furthermore, some questions were difficult for the patients to interpret. The interviewed patients did not report any value from answering the questionnaire. We argue that it may take more than filling out a questionnaire for the patient to feel involved in their own treatment.

Keywords. Patient-reported outcome; osteoarthritis; patient empowerment; PRO

1. Introduction

Patient-reported outcome (PRO) data contain the patient's systematic responses to questions about their health status and quality of life. The Danish definition of PRO is "patient-reported data relating to the patient's state of health including physical and mental health, symptoms, health-related quality of life and functional level" [1,2]. This definition resembles the one from the American Food and Drug Administration (FDA): "a PRO is any report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's responses by a clinician or anyone else" [3, p.2]. PRO data has been used for more than 20 years in Denmark as well as internationally, which means that hospitals, municipalities, and general practices are already working with PRO data. Danish PRO data is supposed to be collected electronically and can be used as a screening tool and/or a dialogue support tool to help the patient prepare for an appointment and to focus on the needs of the specific patient. PRO is also used with the aim of involving the patient in decisions regarding treatment. Furthermore, aggregated PRO data can be used for quality assessment and research as well as benchmarking and management.

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This paper is based on a student project and is carried out in collaboration with Aalborg University Hospital in Farsø [4]. Osteoarthritis is a degenerative joint disease and the most common chronic condition regarding the joints. Osteoarthritis occurs in people of all ages, but is most common in patients older than 65. It is stated that one in two adults will develop symptoms of knee osteoarthritis during their lives and one in four adults will develop symptoms of hip osteoarthritis by age 85 [5]. The use of PRO data can hopefully address the problem that 10-15% of all patients with knee osteoarthritis and 5-10% of all patients with hip osteoarthritis do not achieve the desired result after surgery [6]. Therefore, Aalborg University Hospital in Farsø uses information from PROs in order to predict if the patient will benefit from surgery [6]. The questionnaire is divided into two parts. One part focuses on the knees and the other part on the hips. Each questionnaire uses a combination of the Oxford Hip Score or the Oxford Knee Score and an EQ-5D Index questionnaire. The Oxford Hip and Knee Scores are a validated method and are devised as a joint-specific PRO [7]. The questionnaire consists of 12 questions regarding specific pain, joint problems, and activity limitations. In addition, the EQ-5D is an instrument from the 80's that has been used to describe, value and rate the health of patients. The doctor uses the data when a decision has to be made regarding the patient's future treatment. PRO looks at the patient's medical history and measures risk factors in order to create a data-driven value for the patient [6]. In this paper we examine how the users interact with the system and how they experience the use and usefulness of the system. We observe and interview 7 patients with osteoarthritis and one doctor.

2. Methods

We conducted field observations and interviews inspired by Contextual Inquiry [8]. The data collection consists of observing the patients answering the questionnaire and their communication with the attending nurse. Handwritten fieldnotes of the observed issues and frustrations were made during the observations. After the patients answered the questionnaire, they had their consultation with the doctor. We then conducted semi-structured interviews regarding their experience with the PRO and their dialogue/consultation with the doctor. The data from the interviews with the patient and the doctor were transcribed in order to code the data. Fieldnotes from the observations were included in the coding process. The coding is a mixture of concept-driven coding and data-driven coding [9]. The results of the data-analysis were contained within the following categories: usability, user experience, and value for the patient.

3. Findings

As a result of the usability study, we identified problems and issues regarding the measurement scales and navigation when the patients interact with the system.

There are three measurements scales: the first is for pain during an activity, the second is for pain during rest, and the third is regarding the patient's general health. The measurement scales are difficult to use for the patients, as there is a lack of visual consistency between the different measurements' scales. One is vertical, while the others are horizontal. We suggest that all measurement scales are organized horizontally and

furthermore that the scales would benefit from adding numbers or arrows for better navigation and usability.

Moreover, the general health question seems to be the hardest one to answer for the patient because "general health" is difficult to define, e.g., whether it is concerning this week, this month, or something else. Should the patient include if they suffer from back-pain, etc.? Recommendation for the general health scale is that it could indicate the criteria for each parameter in order to increase the patient's understanding and usage.

The patient also had difficulties with the navigation in the questionnaire. We suggest a visual scroll-down indicator and a clearer progress bar. The patients are then aware of how far along they are in the process of filling out the questionnaire.

4. Discussion

The findings from the data analysis and evaluation do not only concern the usability, of the system. They also relate to the value PRO provides to the patients and the doctor.

During the interview the patients are asked about their experience in completing the questionnaire, e.g., "Do the questions in the questionnaire make sense to you?"; "Do you feel empowered/involved in your own treatment or do you feel any kind of value when answering PRO?"; and "Do you think that the use of the PRO gives you more co-determination in your own treatment?" While the patient generally expressed satisfaction with the visit at the hospital, the questionnaire, and the dialog with the doctor, the answers to the questions were not very specific. Thus, the patients provided us with answers such as "I think so", "I am not sure"," I do not know", and "I guess so".

One of the main purposes of the PRO, according to the Danish PRO secretariat, is to involve the patients in their care and to allow them to be active and autonomous participants in the decision-making process. The implicit assumption seems to be that filling out the questionnaire will stimulate reflection on their health, which again will lead to a better understanding of their own condition and increase patient empowerment. Based on this small study, it seems that the PRO does not fulfill this purpose; the patients state that it does not in any specific way create any value or make them feel more involved in their own treatment.

The data from the PRO questionnaire is used to calculate the Oxford Hip Score and is available on the doctor's screen during consultation. Furthermore, data from other patients, with the same age, gender, and approximately the same Hip Score one year after surgery is presented. Whether the doctor will suggest having surgery depends not only on the HIP Score and statistics, but also on the patients use of painkillers, among other things. The patient must try painkillers before the doctor suggests surgery because the use of painkillers might allow surgery to be avoided.

Data is presented as graphs on the doctor's screen, which are more easily communicated to the patients. However, the doctor does not always choose to show the data to the patients: "If I think that this patient will not understand what it is about, then I keep it out. If it is a patient who I think can understand, I use it as a basis for discussion." For example, a case in which the doctor used the data as a basis for discussion was one in which surgery was recommended, but the patient had doubts. Patients might be so worried that the doctor might decide not to show them the data. When interviewing the doctor, we asked him if the PRO makes it easier for him to decide what treatment the patients would benefit from. He answered, "Not easier, just faster." We also asked the doctor if his patients had experienced a greater satisfaction or increase in quality of life

if they have had surgery and the decision was based on PRO data. The answer was: "I do not know that, because we do not record whether the decision was taken for this or that reason. But perhaps we should do that in the future".

5. Conclusions

We have examined the usability and usefulness of the PRO questionnaire and found several usability issues concerning the use of measurement scales and navigation. We offered suggestions for improving the consistency and navigation within the user interface. We also found that patients had difficulty interpreting the question on general health. Based on the interviews, we discussed the possible value of using the system from the perspective of both the patient and the doctor. Seen from the viewpoint of the doctor, the data and statistics generated from the questionnaires have a clear value in supporting the doctor's decision of whether to suggest having surgery and, in some cases, in communicating with the patient. Seen from the perspective of the patients, the value of the PRO data is less clear. Based on our small study it seems that answering the questionnaire does not add value to the patient's experience of their health situation. We suggest that there is a need for better information about the role of the questionnaire data in the treatment process. More in-depth studies are needed to understand how patients might be influenced by answering the questionnaires and the role of PRO data in the consultation process.

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References

[1] Munch-Petersen M, et al., Videnscenter for Brugerinddragelse i Sundhedsvæsenet, Program PRO: anvendelse af PRO-data i kvalitetsudviklingen af det danske sundhedsvæsen: anbefalinger og vidensgrundlag. Kbh.: Videnscenter for Brugerinddragelse i Sundhedsvæsenet, 2016.
[2] PRO-secretariat webpage. Retrieved from http://pro-danmark.dk/da/pro-english on August 2, 2019.
[3] U.S. Department of Health and Human Services Food and Drug Administration Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims, U.S. FDA, Clinical/Medical 2009. Retrieved August 2, 2019. from https://www.fda.gov/downloads/drugs/guidances/ucm193282.pdf.
[4] Andersen NS, Bøgh Pedersen SJ, Holm-Thomsen L, Macek D. PRO – A new way of working. Master of programme in Information Studies, 2018, 7. Semester, Aalborg University, December 2018.
[5] Osteoarthritis Foundation, Osteoarthritis: Arthritis Foundation, 2018. Retrieved on December 9 from http://www.arthritis.org/about arthritis/types/osteoarthritis.
[6] Steenberger A, Før: Hvordan gik operationen? Snart: Hvordan har patienten det?, (2017), Retrieved August 2, 2019.from https://www.cok.dk/sites/cok.dk/files/2018-05/Artikel%20om%20Farsø.pdf.
[7] Murray DW, Fitzpatrick R, Rogers K, Pandit H, Beard DJ, Carr AJ. Dawson, The use of the Oxford hip and knee scores. The Journal of Bone and Joint Surgey, British 2007;89(8): 1010-10-14.
[8] Holtzblatt K, Beyer H. Contextual design: Design for life, (2nd ed), Elsevier Cambridge, MA, 2017.
[9] Gibbs G. Thematic Coding and Categorizing. In Analysing qualitative data, Sage London, 2007, 38-55.